

## **Parent Professional Collaboration In Children's Mental Health**

### **The Role of Family Advocates**

#### ***Introduction***

System of Care is fundamentally changing the relationships families have to the service system every level. Collaboration and partnership between families and service providers is the thread that links successful programs, policies and practices. Many federal and state policies mandate parent involvement. Parents now provide services, act as advocates for change, mentor other families, shape programs, create policies and carry out public service agendas. Parents and professionals working collaboratively as partners are now recognized as a best practice. These collaborative partnerships have resulted in measurable and direct positive benefits for families, children and providers.<sup>1</sup>

This paper addresses the role of Family Advocates within the children's mental health system. It explores the research that documents this unique and vital role --- families as equal partners in improving the outcomes for children with emotional and behavioral disturbances and their families.

#### ***North Carolina's Response***

*"As we continue to advance the values and practice of system of care in North Carolina it is critical that parents of children with severe emotional disturbances be embraced as valued and necessary partners in our endeavors. The role of parents range from individual level peer support to more global efforts such as systems planning and improvement efforts, community capacity development and policy leadership".*

*Richard Visingardi, Director, NC Division MH/DD/SAS*

More than 200,000 children under the age of 18 in North Carolina have a serious emotional disturbance. These children are at substantially greater risk for school dropout, school expulsion, drug or alcohol abuse, unplanned teen pregnancy, and conviction of crimes. When a child experiences a serious emotional disturbance the life of the entire family is changed. A recent North Carolina study reported that caring for children with emotional disorders takes a toll on the child's family, causing harm to the family's well being. The effects tend to worsen over time, suggesting that the families and caregivers do not get used to caring for their children.<sup>2</sup> Our current systems are often ill-equipped to deal with the multiple and varied needs of these children and their families. Feelings of isolation, frustration and anger are the norm as families attempt to find help for their children and support for themselves.

North Carolina's mental health system continues to undergo reform and reorganization to better serve families and children through a System of Care approach. This approach, with family partnership at its core, has been successfully piloted in 22 North Carolina counties. The resulting outcomes led to the adoption of the System of Care approach as a key reform element in the State's mental health reorganization plan. The State Mental

Health Plan - 2002 has identified the following as core requirements and /or values for the future provision of children's mental health services.

- Families will have meaningful input in all aspects of the planning, delivery and evaluation of services.
- Families and professionals working together maximize the benefits of the services rendered.
- Utilize “best practice” models that include family support, family education and family training.
- Create support systems to ensure family participation.

### ***What is Family Advocacy?***

***“A family advocate has personal experience in dealing with a child that has an emotional, behavioral, and/or mental health challenge. The family advocate has walked the walk, learned from the experience of the journey, and is willing to help other parents or caregivers benefit from their experiences.”***

***Pat Solomon, Coordinator, NC Families United***

Family Advocacy, simply put, is a mechanism for peer social support. Social support as defined by Brown, 1996 is ... social relationships... information, nurturance, empathy, encouragement validating behaviour, constructive genuineness, sharedness and reciprocity, instrumental help, or recognition of competence. Increasing social support is a time-honored, well-respected method of enhancing treatment options. Peer support has been the cornerstone of the developmental disability field since 1975 when Parent-to-Parent support groups were instituted. This model of peer support and advocacy is used with great success in many other health and human service disciplines. 3,4,5

The most highly recognized and successful use of the peer support strategy is Alcoholics Anonymous (AA). AA pairs recovering alcoholics with a sponsor, a person who has experienced alcoholism and who has maintained sobriety. Through the use of individual and group meetings, AA is one of the longest running programs and claims a high success rate.<sup>6</sup> It is important to note that family advocacy in mental health doesn't replace professionals or treatment. However, family advocacy is designed to enhance that work by providing parent-to parent support, nurturing and access to informal resources. It is a community-based strategy in the continuum of care for children and families.

Many national and state organizations have championed the important role of families in providing supportive services to help families thrive. In the values promoted by the national and state organizations of The Federation of Families for Children's Mental Health, NC First in families, North Carolina Council on Developmental Disabilities, NC Family Support Network and Family Support America, strategies to support families include:

- Parent-to parent advocacy groups
- Family self-help support
- Information and referral

- Education and Advocacy

### ***What Do Family Advocates Do?***

Family Advocates in the mental health system work with other families either one-on-one or in groups. They meet with families in their homes, in their communities and may accompany families to professional meetings related to the child's health and treatment. Family Advocates also sit on policymaking, planning and oversight boards at the local, state level and national levels.<sup>7</sup>

#### **Family Advocates**

- **Provide emotional and informational support**
- **Identify unmet needs and create ways to meet those needs Link parents to other parents and community based and professional resources**
- **Provide education opportunities that help parents understand related issues and laws**
- **Support service providers and the treatment plan**
- **Advocate for individual families and for fair and responsive policies that affect all families**

Family Advocates provide services in several ways.

#### **Parent Run Support Groups**

Family Advocates implement and staff support groups for people who are raising children with an emotional or behavior disturbance. In these groups, adults and sometimes youth get together to share emotional support, information, practical strategies and resource options. Parents develop the group and run the meetings themselves, offering opportunities for informational and emotional sharing.

#### **One-on-One Parent Support**

One-on-One Parent support or mentoring is parent directed and delivered support. This

support can take many forms, intellectual and emotional, tangible and intangible. In

individual support, trained parents are matched with parents newly referred to the program or organization.

#### **Support Professionals in Service Delivery**

Family Advocates work with professionals to provide the additional time needed with the family to enhance the treatment plan. Family Advocates can partner with the professional in a way that allows the professional to focus on their area of expertise while the Family Advocate provides social and other supportive services.

#### **Advocacy**

Advocacy is defined as "speaking for another person or cause".<sup>8</sup> With the many complex issues and stigma surrounding parenting children with serious emotional disturbances, many families need support in advocating for themselves and their child. Family Advocates may attend school and human service meetings with the parent. They may

also provide education on the laws that protect the rights of the families and children. Family Advocates also speak for issues and concerns that professionals may not be able to voice regarding changes in the service system policies, practices and funding. Family members contribute integrity to policy group work by providing reality-based, culturally relevant information from a perspective that no one else has.<sup>9</sup> In North Carolina families are required members of Community Collaboratives, the local decision making bodies in the System of Care and of Consumer and Family Advisory Committees. <sup>10</sup>,<sup>11</sup>

Why Does it Have to be a Family Member?

***“The world of being a parent of a child with serious emotional or behavioral issues is challenging, frightening and very lonely. Your child is often viewed as a ‘bad kid’ or you are seen as a less than adequate parent. Meeting and talking with other parents who are experiencing similar issues can bring some comfort and strength that no other connection can bring. These conversations bring a source of unique support - of one parent speaking with another who knows, really knows, because of their own life experiences. It is an opportunity to share ideas and resources along with just ‘letting your hair down’ with one another. It can bring a restoration and renewal that allows you to continue walking tall to help your child and your family.”***

***Elizabeth Vickery, Mother***

Parents raising a child with emotional or behavioral disorders often experience anxiety, frustration and isolation. It can be overwhelming to navigate the medical, school and sometimes legal system on top of completing the tasks of daily life. Sharing experiences with others in similar circumstances is a source of relief and lessens the sense of isolation. There is an automatic understanding of the visceral and practical issues that accompany being a caregiver of a child with an emotional or behavioral disorder.

It is because of this “automatic understanding”, that when asked, parents of young children with disabilities state that the first choice of receiving emotional support is from other parents who have had or who are having the same or similar experience as they.<sup>12</sup>

Why Professionals and Family Advocates Work Together?

***“The implementation of the System of Care Model is founded on the complete and honest involvement of each child’s community and family in the decision-making process. Under this model families and professionals are encouraged to form a partnership that allows the identification of the strengths and needs of the child, family, and community. This partnership is crucial to the development of a successful treatment process. Families and professional are respected for the special knowledge and talents that each brings to the treatment process. Families are seen as valuable resources in the***

***service provision arena. Beyond advocating for their individual child, families can offer effective support and education to others seeking to navigate the community service system. Effective partnerships between families and community partners create positive***  
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***outcomes for children, families, and communities. In a very real sense, each family's experience represents an outcome measure from which we can all learn."***

***Michael Watson, CEO, Sandhills and Randolph Center for MH/DD/SAS Services***

Mental health services are generally time-limited while the family and the community are constants in a child's life. Drawing effectively on parent and community resources enhances the likelihood that treatment combined with family support will promote better outcomes. 13 Professional and families working together can create home and community- based alternatives that supplement formal services and that provide structure as well as nurturing and support. As budgets shrink and needs grow, family advocacy can help decrease the workload of the professional by expanding the treatment options.

*Who Benefits from Family Advocacy?*

Families report that they receive services earlier, identify more community resources and more clearly understand parenting issues after working with a Family Advocate. 14 The Beach Center, a respected research institution, found that more than 80% of the parents interviewed in their study found Parent-to-Parent support helpful.15 Principal findings of this research also shows that parent-to-parent support increases parents' sense of empowerment, acceptance of their situation, and their own capacity to cope. The children are the direct beneficiaries when parents are better informed and better able to cope.

According the Family Support America, Federation for Families and other national sources the benefits of family involvement and advocacy are clear.

Benefits

Conclusion

Family Advocacy is a respected and effective strategy to provide support and education to families of children with serious emotional and behavioral disturbances. It is but one component

### **For Families For Professionals**

Increased knowledge of children's disorder Improves ability to accomplish mission

Opportunities to network with other families Saves money by extending resources

Increased confidence in parenting skills Improves quality of service

Increased knowledge and skills Develops a constituency that can advocate

Create sense of belonging Decreases workload

Increase sense of personal power Contributes to the stability of the community

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in a continuum of family involvement. However, it is the component that has been implemented the longest, gained the greatest acceptance and been adopted most freely. The benefits for families, children, providers and systems are so well documented that family involvement is an

integral piece of the foundation for NC 's mental health reform movement.

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